



The NHS Friends and Family Test: guidance on handling the Friends and Family Test in sensitive situations

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Contents

1	Introduction.....	5
2	Background	5
3	The issue.....	5
4	Recommendations for providers and FFT suppliers.....	6
	• Recommendation 1: Exclude cases that are likely to cause upset.....	6
	and distress.....	6
	• Recommendation 2: collecting and handling FFT data with high	7
	standards of privacy, confidentiality and ethics	7
	• Recommendation 3: Apply the key principles of the Market.....	8
	Research Society Code of Conduct	8
5	Summary and next steps.....	9

1 Introduction

The purpose of this paper is to offer NHS providers and suppliers of the Friends and Family Test (FFT) further guidance on how best to handle the FFT in sensitive situations. It recommends that providers and FFT suppliers exclude certain cases from the FFT to avoid causing unnecessary distress to patients, users and their families. It provides some guidance on the use of telephone methods and digital/automated technology. It also provides a recommendation that providers and suppliers delivering the FFT follow the principles of the Market Research Society Code of Conduct.

This paper should be read alongside the original guidance on implementing the FFT: <http://www.england.nhs.uk/ourwork/pe/fft/fft-guidance/>.

2 Background

The Friends and Family Test is a flexible tool, enabling providers to seek feedback from their patients in a way that best suits the needs of their organisation. Whilst NHS England does set some mandatory requirements about the collection and reporting of the FFT, it does not recommend a single methodological approach. Providers may choose a range of methodologies to deliver the FFT at a local level. They are permitted to conduct the FFT in house, or use an external supplier. To ensure that the FFT is accessible to all, NHS England permits multiple methodologies within a single organisation, but recommends that the approach is consistent over time.

Whilst NHS England does not prescribe a single methodology, it did mandate that token methods should not be used to capture FFT feedback from 1 April 2015, due to concerns about this method.

Providers therefore have adopted a range of methodologies to deliver the FFT, including paper based forms, text messaging, and online surveys. Many providers employ a variety of tools to increase participation and are using traditional paper methods alongside new technologies. Many providers have embraced digital solutions, such as text messaging, automated voice systems and mobile applications.

There are many advantages and disadvantages associated with digital methods of capturing feedback. The benefits to NHS organisations are numerous: digital methods are less resource intensive and easy to administer; they can capture feedback quickly; the results are available almost instantaneously; and they encourage participation from certain groups of patients, particularly young people. However, due to the very nature of digital systems, and the large volume of patients that can be contacted, errors can occur.

3 The issue

A number of issues have been raised about the use of the FFT in sensitive situations. NHS England is aware of a number of incidents and stories reported in the local and national media where the FFT has been used inappropriately. Whilst NHS England

recognises that some of these cases were unfortunate coincidences that could not have been avoided, other such cases could have been easily prevented.

A number of specific cases were reported that involved deceased patients or recently bereaved patients being contacted to give FFT feedback and there have been some concerns raised about potential breaches of patient confidentiality. Many of the cases involved either a text message or an automated telephone voice message. The contact might also be more distressing for the patient due to the real-time nature of the FFT and the impersonal nature of these methodologies.

The FFT guidance published in July 2014 (and updated March 2015) makes it very clear that the FFT should **not** be offered in sensitive situations, and allows clinical discretion in cases where the patient is not physically and/or mentally well enough to participate, or where participation might cause further distress. Women who experience still birth or miscarriage should **not** be offered the FFT as a matter of course, due to the timing of the FFT and the method of delivery.

The guidance also stresses that patients in sensitive situations should not be excluded from providing feedback per se, but that the real-time nature of the FFT, and the method of delivery, might not always be appropriate. Consideration should be given to alternative means of seeking feedback from these groups of patients.

4 Recommendations for providers and FFT suppliers

To avoid causing any further unnecessary upset or distress to patients, service users and their families, NHS England recommends that providers and suppliers should:

1. **routinely exclude cases that are likely to cause upset or distress;**
2. ensure high standards of privacy, confidentiality and ethics when collecting and handling FFT data;
3. follow the key principles of the Market Research Society Code of Conduct.

NHS providers and suppliers of the FFT are expected to implement these changes as soon as it is reasonably possible.

Recommendation 1: routinely exclude cases that are likely to cause upset or distress

NHS England recommends that providers and suppliers of the FFT exclude cases that are likely to cause upset or distress to patients and service users, their carers and their families, as a matter of course.

Examples of cases that should be routinely excluded from the FFT are provided in the table below. This is not an exhaustive list and judgement will need to be applied on a case-by-case basis.

It is important that the FFT remains an inclusive tool and is available to all those who wish to give feedback. NHS England recognises that the timing and method of the FFT might not always be appropriate for some patients and service users and

alternative methods of collecting feedback should be offered at a later, more appropriate time.

Cases to be routinely excluded from the FFT

It is not possible to identify every scenario where it might be inappropriate to offer the FFT; clinical discretion and judgement should still be exercised on a case by case basis

- Deceased patients. The FFT sample should be re-checked as close as is reasonably possible before contact is made.
- Women who have experienced a miscarriage, still birth, or neonatal death (to include women who present at A&E, are treated or admitted to hospital, as well as those already excluded at the FFT maternity touch-points). These patients could be offered the opportunity to provide feedback at a later, more appropriate time.
- Where it is possible to identify, patients following the diagnosis of cancer, or other serious, life-threatening or life-changing condition. These patients could be offered the opportunity to provide feedback at a later, more appropriate time.
- Where it is known that a patient is recently bereaved, including for example where they might have been treated at the same time as a family member (e.g. following a car accident).
- Where there are duplicate telephone numbers within a sample (i.e. where a person has accessed a number of services), to avoid a patient or service user being contacted multiple times.
- Where there isn't sufficient information to identify the patient or service user (i.e. an initial instead of a first name, or a surname only).
- Any patient known to have requested their details are not used for any purpose other than their clinical care; or who have opted out of the FFT at any time.

In some circumstances, where it is difficult to identify the patient through existing records, the staff caring for the patient could contact the appropriate person within the trust or the supplier to delete the contact details from the sample.

Recommendation 2: collect and handle FFT data with high standards of privacy, confidentiality and ethics

Providers and suppliers of the FFT must ensure that the same high standards of privacy, confidentiality and ethics apply to telephone, digital and automated methods of data collection, as they do with other forms of communication.

The FFT is a feedback tool and market research principles should always apply (see recommendation 3). Given the highly personal and sensitive nature of healthcare, digital methods of communication should be carefully considered. Often digital methods have been developed for other purposes, such as for marketing, sales, or advertising and are not appropriate in this context. Automated dialler systems (such as predictive diallers) are not recommended for the FFT.

Guidance on using telephone methods and digital/automated technology

- Calling or sending text messages to a mobile phone for the purpose of collecting feedback should follow the principles of respect and disclosure that are expected for landlines (e.g. identify the caller, explain the purpose of the call, the voluntary nature of participation, the guarantee of confidentiality and consideration of appropriate times for contact).
- Do not leave voice, automated or text messages on phones that disclose the person has been a patient/service user, or been in contact with healthcare services. Any message should contain minimal information to protect patient confidentiality as these messages could be accessed by others.
- Telephone calls – to protect patient confidentiality ensure you are contacting the right person by verifying their identity prior to disclosing any information that suggests they have been a patient/service user, or been in contact with healthcare services.
- If a person opts out of further contact via text message, or other method, this should be recorded on the original contact/sample list to avoid patients being re-contacted at a later date following any subsequent episode of care.
- Automated dialler systems are not recommended.

Recommendation 3: apply the key principles of the Market Research Society Code of Conduct

Providers delivering the FFT in-house, or contracting with a third-party to deliver the FFT, should follow the key principles of the Market Research Society Code of Conduct

The FFT is a feedback tool and therefore market research principles should always apply. The principles that govern market and social research are different and separate from the principles that govern marketing, sales, and advertising.

Market and social researchers are expected to follow the principles set out below.

Principles of the Market Research Society Code of Conduct

1. Researchers should ensure that participation is based on voluntary informed consent.
2. Researchers should be straightforward and honest in all their professional and business relationships.
3. Researchers should be transparent as to the subject and purpose of data collection.
4. Researchers should respect the confidentiality of information collected in their professional activities
5. Researchers should respect the rights and well-being of all individuals.
6. Researchers should ensure that respondents are not harmed or adversely affected by their professional activities.
7. Researchers should balance the needs of individuals, clients, and their professional activities.
8. Researchers should exercise independent professional judgment in the design, conduct and reporting of their professional activities.
9. Researchers should ensure that their professional activities are conducted by persons with appropriate training, qualifications and experience.
10. Researchers should protect the reputation and integrity of the profession.

For further information see: https://www.mrs.org.uk/standards/code_of_conduct/

5 Summary and next steps

It is important to consider the methods used to deliver the FFT overall and to identify the range of needs and circumstances for everyone who may be approached to complete the FFT. Depending on the individual situation, it might be more appropriate to use alternative methods to support the completion of the FFT, particularly when the patient or service user has specific communication needs. NHS England has recently updated the FFT implementation guidance to provide further advice to providers and FFT suppliers: <http://www.england.nhs.uk/ourwork/pe/fft/fft-guidance/>.

It should also be highlighted that patients in sensitive situations should not be excluded from giving feedback, and that alternative tools may be utilised at a later, more appropriate time to ensure that all patients who want to share their experience are given a range of options and methods.

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NHS providers and suppliers of the FFT are expected to implement these changes as soon as it is reasonably possible. NHS England will communicate this paper to FFT regional teams, the FFT supplier forum, existing FFT networks, and via the FFT monthly update. The FFT implementation guidance will be updated with the information in this paper at the next available opportunity.

NHS England will continue to monitor any further incidents and complaints about the FFT and consider any additional further action, if needed.

If you have any queries about this guidance, or the FFT in general, please contact NHS England via email at: england.friendsandfamilytest@nhs.net.